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## Edinburgh Research Explorer

### **What does the autism community think of research with infants with higher likelihood of later autism diagnosis? Results of a large international survey.**

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# Engaging in Autism Research

What does the autism community think of research with infants with higher likelihood of later autism diagnosis? Results of a large international survey

*Sue Fletcher-Watson*

*IMFAR 2015, May, Salt Lake City*

*Panel: Understanding early dyadic interaction in ASD*

A faint, stylized map of Europe and the Mediterranean region serves as the background. It shows major landmasses, bodies of water like the Norwegian Sea and Mediterranean Sea, and some country names such as Norway, Sweden, Finland, and Turkey. A dark blue horizontal bar is positioned across the upper middle of the image, containing the title.

# Collaborators

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# Early dyadic interaction

- Data derived from studies of “high-risk” infant groups
- Parental style may be influenced by knowledge of genetic factors (for siblings), perceptions of autism...
- Potential delivery route for pre-diagnosis intervention
- Interpretation regarding parent responsibility for child's development

# Ethics of early autism research

- Relationship between researchers and participants
  - Longitudinal studies; intense commitment
  - Focus on younger child
  - Sharing information about early signs of concern
- Intervention component
- “at-risk” language
- Perspective of participants as they grow up

# Objectives & Method

- Explore the attitudes of the autism community to early autism research
  - Contrast attitudes between stakeholder groups
  - Relate attitudes to research to underlying factors such as service provision
  - Produce guidelines for researchers
- Online survey developed from focus groups
  - Single survey suitable for a range of respondents
  - Ease of translation of responses – mostly multiple choice formats
  - Participants forced to self-categorise in one group

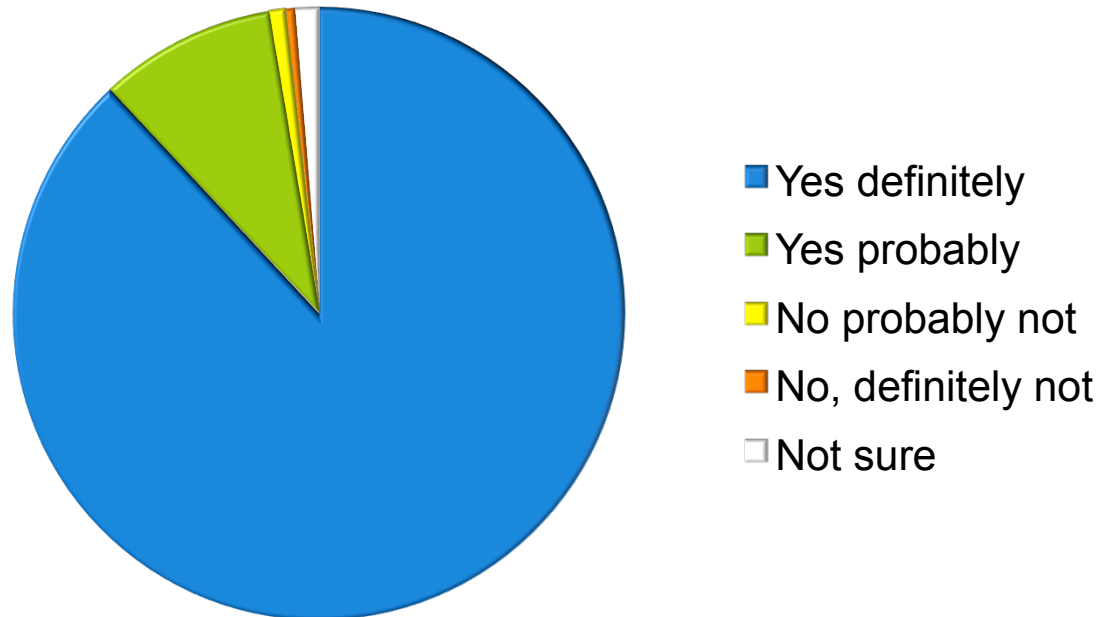
n=2317	Practitioner	Parent	Teacher	Autistic Adult	Other	%
Czech Rep	31	122	42	9	-	8.8%
Finland	50	97	43	38	-	9.8%
France	37	99	7	2	1	6.3%
Italy	71	40	9	1	5	5.4%
Israel	20	10	15	-	-	1.9%
Macedonia	6	10	-	-	-	0.7%
Norway	59	91	46	8	11	9.3%
Poland	138	103	37	4	2	12.3%
Portugal	124	76	182	3	34	18.1%
Spain	53	225	45	6	34	15.7%
UK	50	167	16	30	8	11.7%
Total n	639	1040	442	101	97	
%	26.0%	42.2%	14.6%	4.9%	12.3%	

Mostly female = 82%  
Mean age = 40.5 years

> 5 years experience with ASD:  
Practitioners = 66%; Teacher = 47%

# Overall attitudes

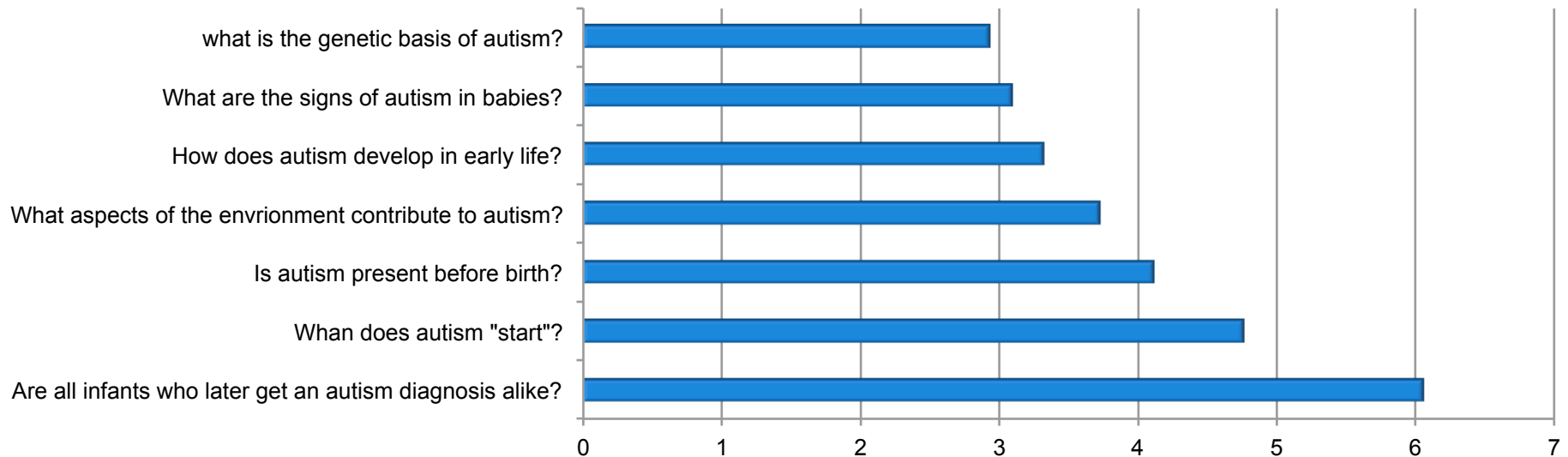
*Do you think research into the early signs of autism should be done?*





# What should we be researching?

*What are the most important questions scientists should be asking about early autism?*



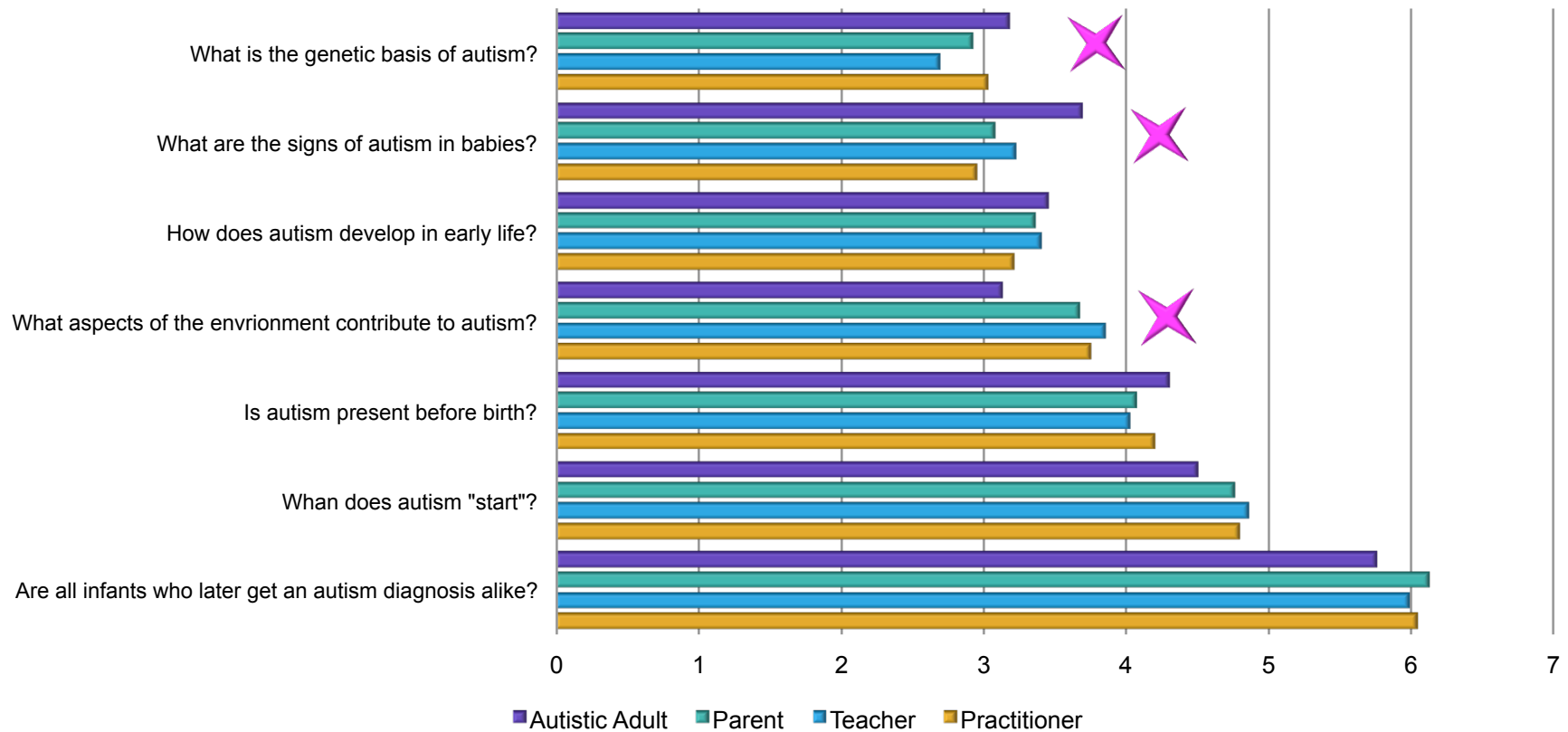
# Stakeholder differences

*Do you think research into the early signs of autism should be done?*

	Practitioner	Parent	Teacher	Autistic Adult
Yes definitely	576 (90.6%)	384 (87.7%)	910 (88%)	69 (68.3%)
Yes, probably	43 (6.8%)	42 (9.5%)	99 (9.6%)	26 (25.7%)
Probably not	5 (0.8%)	6 (1.4%)	7 (0.7%)	2 (2%)
Definitely not	2 (0.3%)	2 (0.5%)	6 (0.6%)	1 (1%)

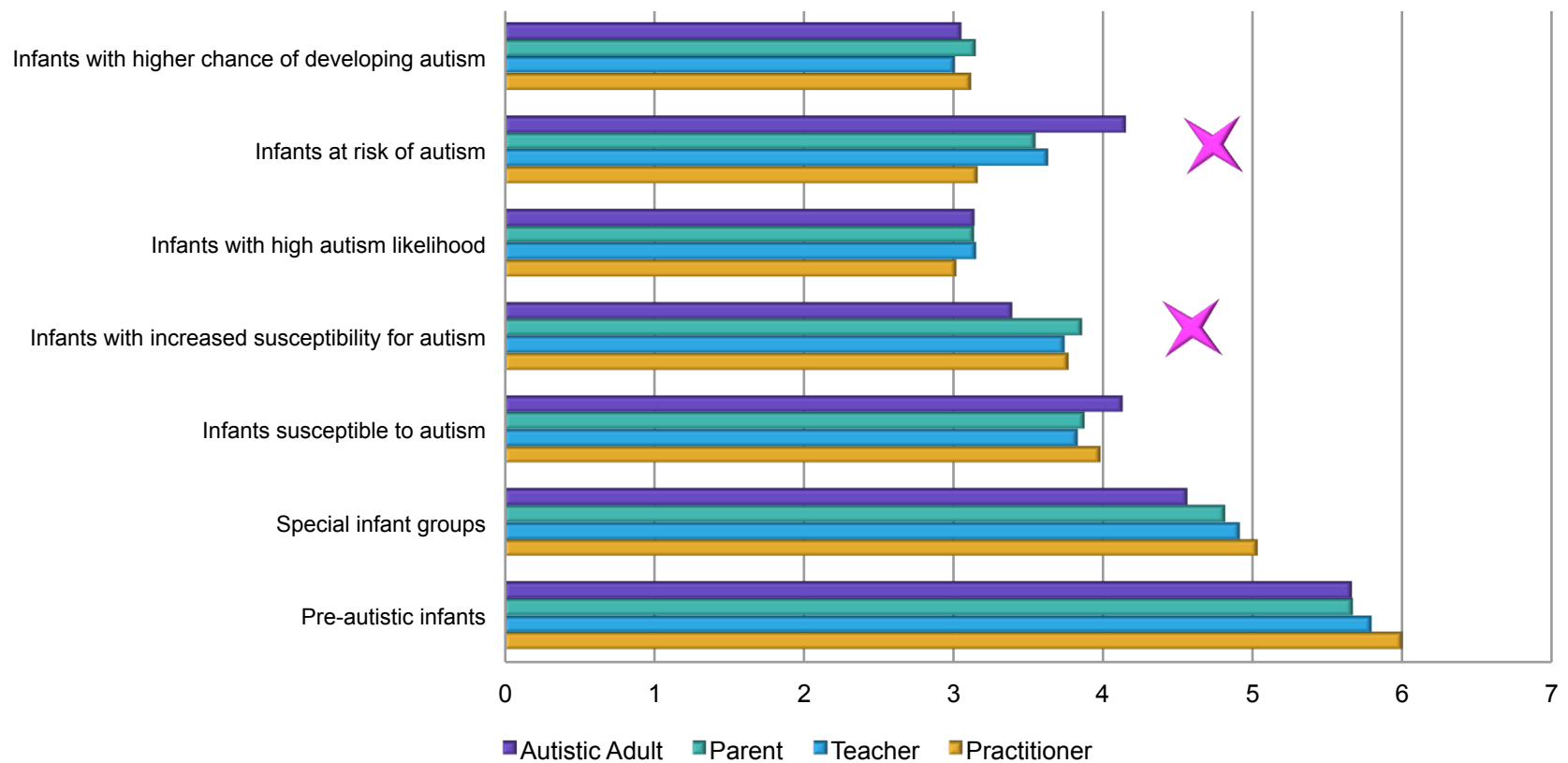
Wald  $\chi^2 = 1.15$ ,  $p < .001$

# What should we be researching?



$\chi^2 > 35, p < .005$

# What about language?

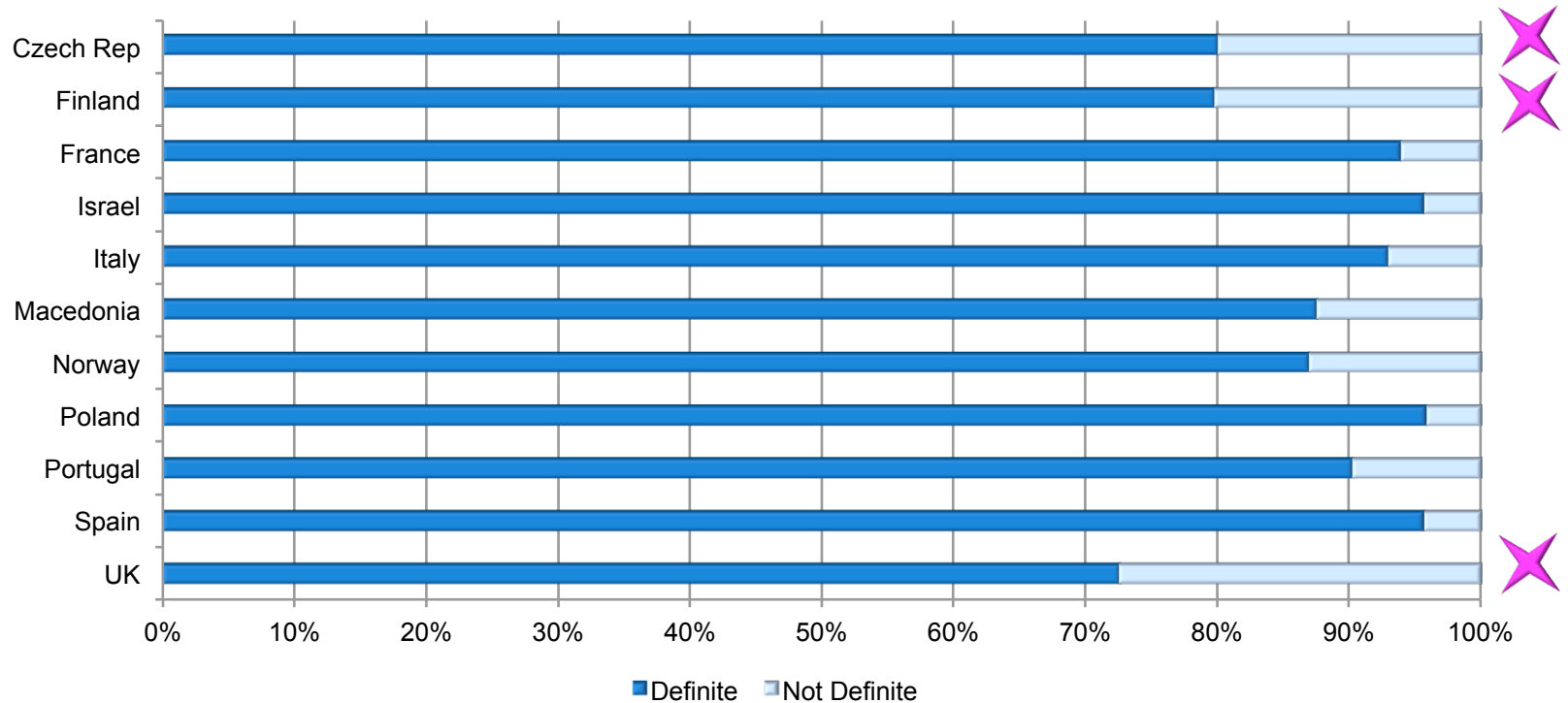


$\chi^2 > 35$ ,  $p < .01$ , practitioner effect for “at risk”

# Predictors of attitudes

- Dichotomous split into Definite (n=1939) and Not Definite (n=270) supporters of early autism research
  - Only n=31, (1.4%) responded negatively
- Predictors: country, gender, age, stakeholder group
- Country was significantly associated with attitudes, Wald  $\chi^2 = 67.81$ ,  $p < .001$ , OR = .837

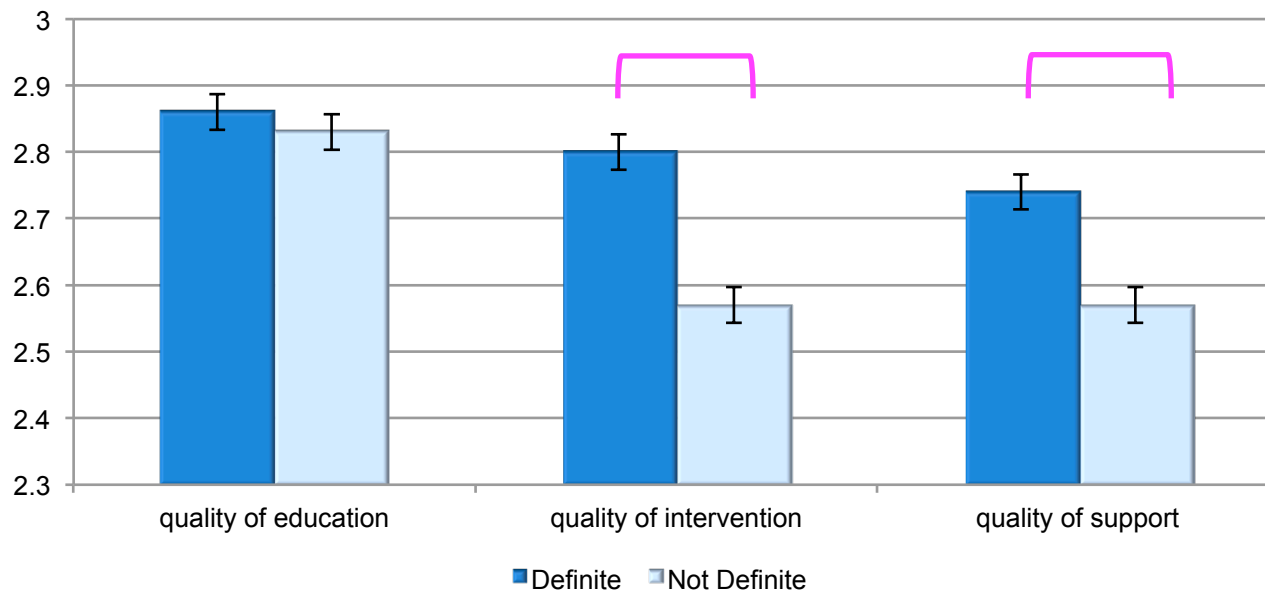
# National Differences?



Largest stakeholder groups: UK and Finland, but not Czech Republic...

# Effect of service quality?

Not a significant predictor of attitude, but group differences are apparent

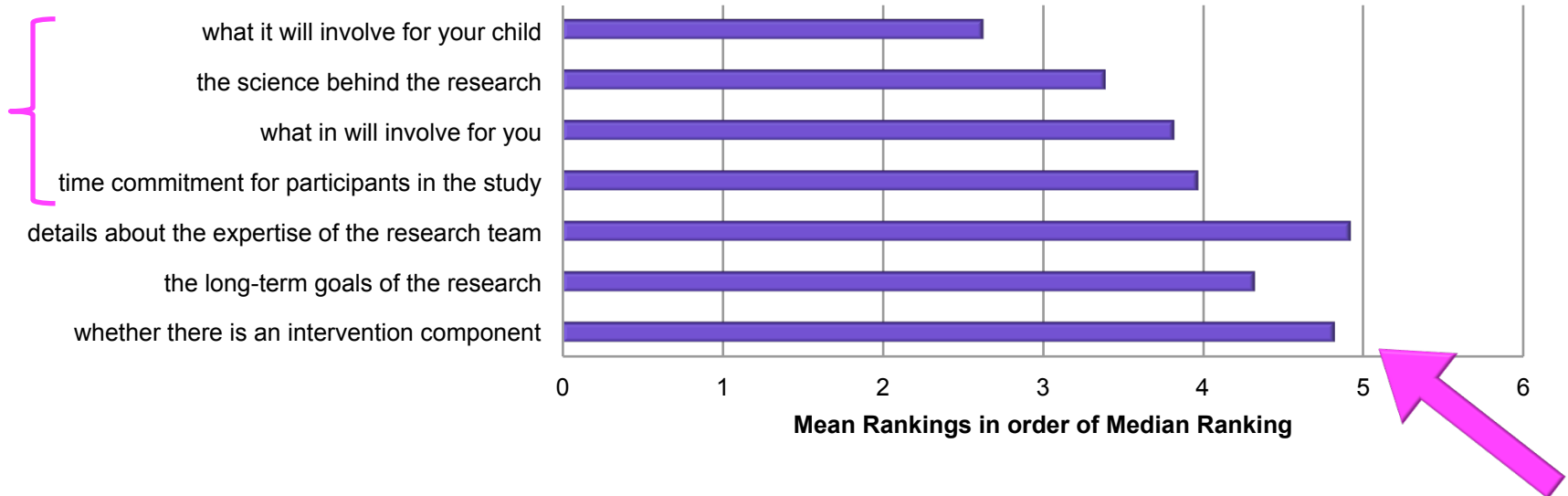


Intervention,  $t(203.6) = 2.93$ ,  $p = .004$

Support,  $t(200.3) = 2.01$ ,  $p = .046$

# Focus on parents I

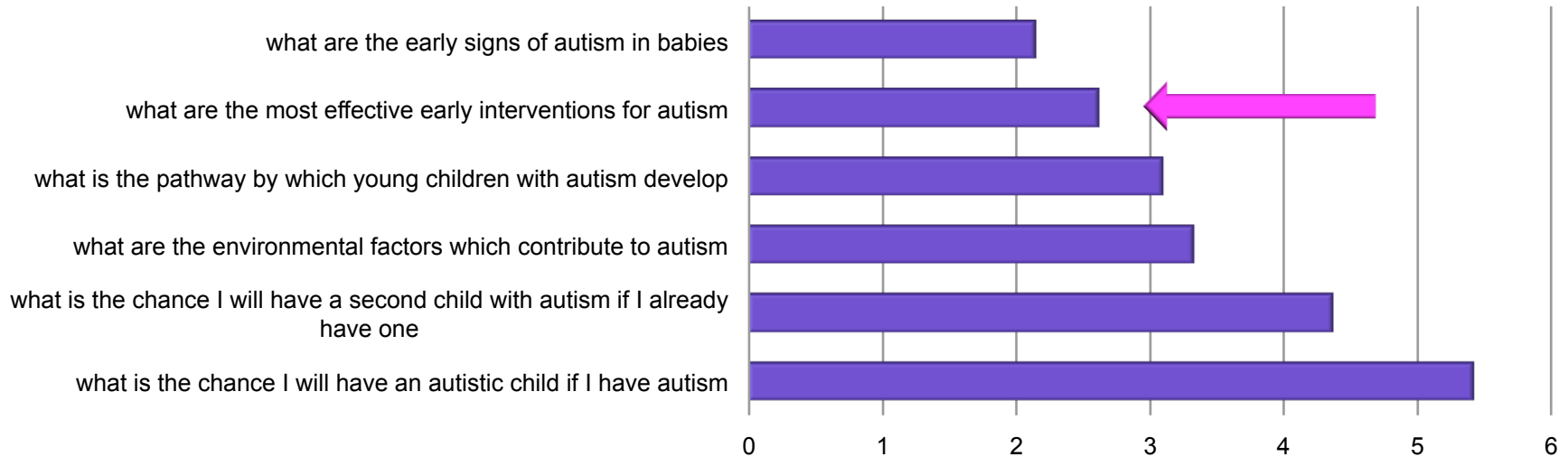
## Information which influences decisions to be involved in research



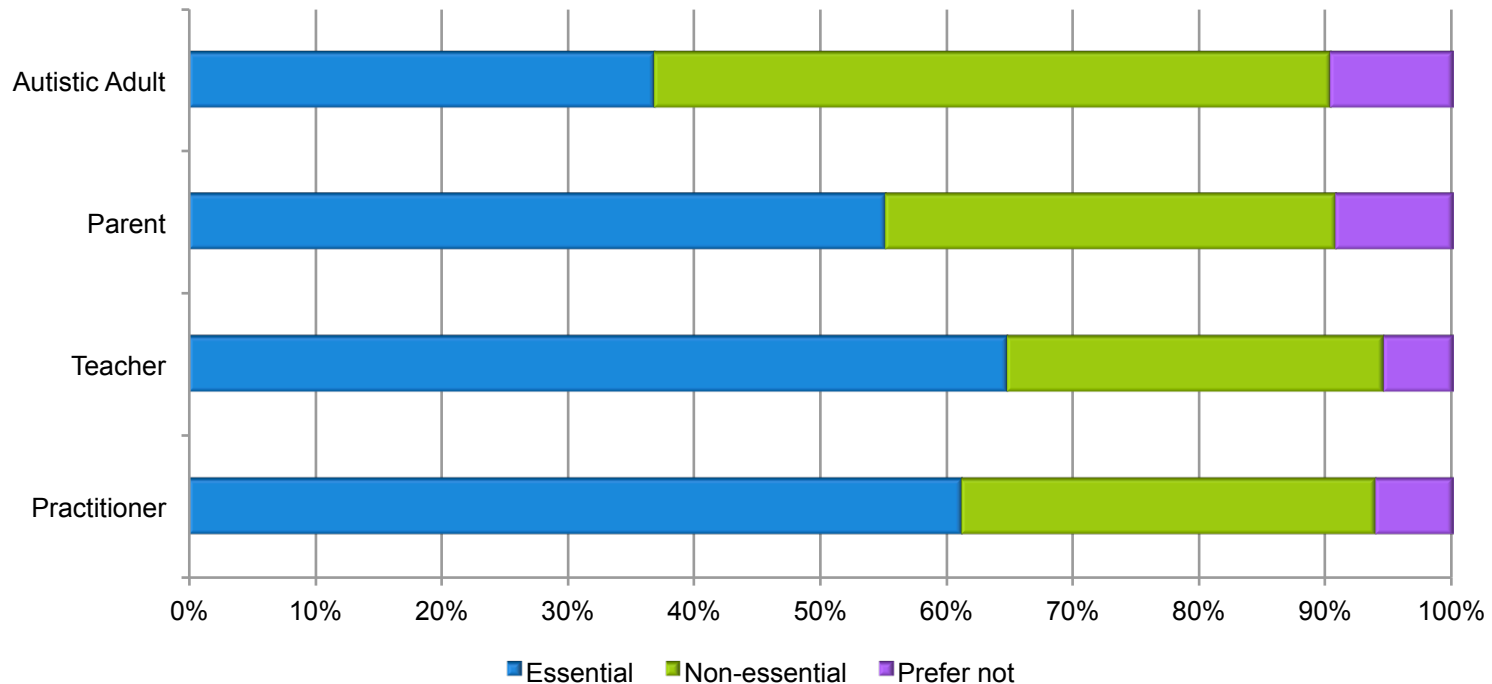


# Focus on parents II

## Practical information wanted from research



# What about Intervention?



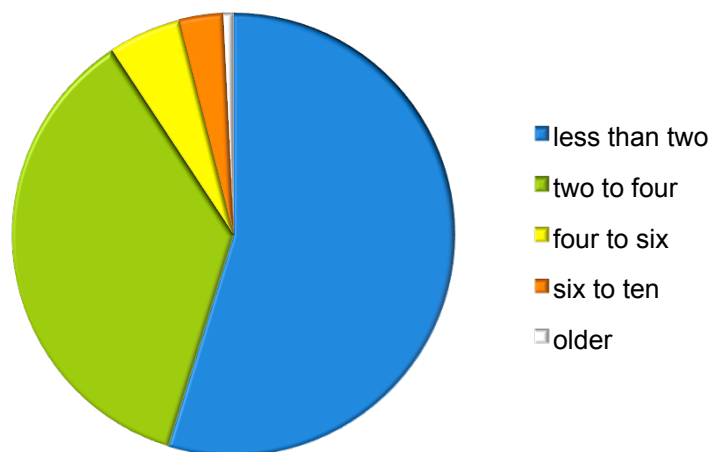
Parents like to be in control: at home, or parent-training preferred

# The participant experience

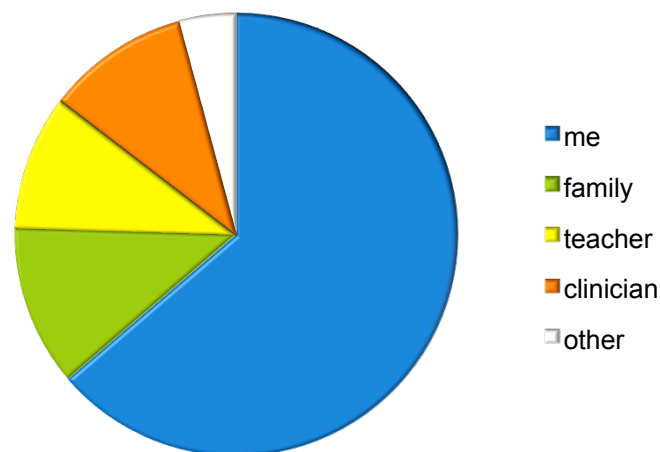
- Direct benefits for participants
  - Detailed profiles for the child with autism, but no interest in profiling for other children
  - Access to intervention (essential for 55%)
- Sharing information with participants
  - 82% support full disclosure of all scores and reports
  - 46% additionally want general study findings
  - Only 8% support sharing information with a family doctor instead

# Why support early autism research?

- Mean age of diagnosis = 4.73 years, SD = 4 years
- 90% reported concerns raised before 4 years old
- 75% reported that concerns were first raised by the parent or another family member



Concerns first raised...



Concerns raised by...

# Key Findings

- Stakeholder attitudes are not necessarily as expected (?) and show high levels of engagement with scientific goals
- High level of consistency between stakeholder groups in most topics covered
- Autistic adults most often have a different perspective
  - continued enrollment of children in longitudinal studies?
  - Perspective of participants looking back from adulthood?
- Additional analysis required
  - Comparison across countries
  - Clarification using open-ended responses

# Interim Recommendations

- Researchers need to consider
  - Intervention component
  - Greater transparency & communication with participants
  - Changing the use of “at risk” language
- Responding to community priorities may conflict with traditional research ethics
  - Changing research ethics?
  - Public engagement with science?
- Projects such as this provide a solid ethical and community engagement foundation for research

# Thank you!



[www.dart.ed.ac.uk/ear-project](http://www.dart.ed.ac.uk/ear-project)



ESSEA

(Enhancing the Scientific Study of Early Autism)

COST Action BM1004